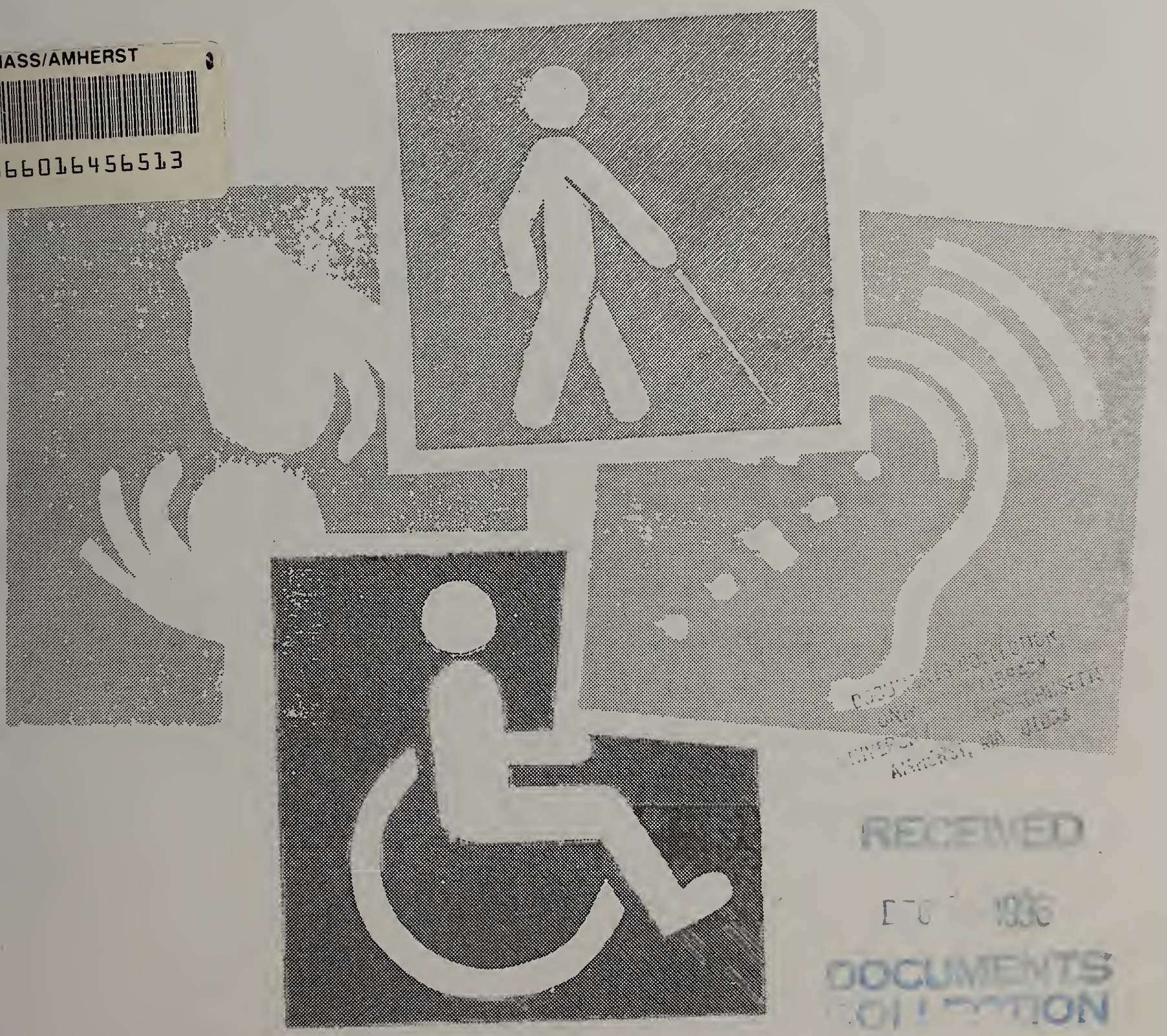
THE GOVERNMENT WE LOSE:

INCREASING ACCESS OR CREATING BARRIERS?



A BOOKLET FOR

THE MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL

PRODUCED BY

THE MASSACHUSETTS HUMAN SERVICES COALITION

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The Government We Lose:
Increasing Access or Creating Barriers?

A booklet for the Massachusetts Developmental Disabilities Council produced by the Massachusetts Human Services Coalition

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Addendum

Through an editing oversight, the following section was inadvertently omitted from the booklet The Government We Lose: Increasing Access or Creating Barriers. We apologize to readers and to this section's author, Kyle E. McHugh, for this error.

Massachusetts Commission for the Blind (MCB)

The Commission for the Blind would be moved to the Secretariat of Family Services in the Department of Disability Services. It would be combined in this department with the former Department of Mental Retardation, Commission for the Deaf and Hard of Hearing and the Massachusetts Rehabilitation Commission.

The Commission would lose its current independent status when it is relocated to the Department of Disability Services. Although this new department would include an entity called "Bureau of the Blind," this would simply be a title for a category of service which indicates no independence.

MCB currently has a very efficient system of entry for new clients, so this department will not necessarily benefit from the new single-point-of-entry system. Since eye doctors in Massachusetts are currently required to report all patients who reach a certain diminished level of visual acuity to MCB, potential clients are easily contacted. Patients with a dual diagnosis may in fact face more delays and confusion if separated from the current system.

Administration of Supplemental Security Income (SSI) for the blind would no longer be the responsibility of the MCB. SSI determination and administration would be handled by the new Department of Transitional Assistance (DTA) in the Secretariat of Family Services.

Management of SSI for the blind would be combined with that of all other disabilities and emergency welfare assistance under DTA. This could lead to a standardization of SSI grants in order both to simplify the system and to allow the state greater flexibility in determining the state contribution to this federal program. In this case, blind recipients of SSI are in danger of a reduction in their SSI payments, which are currently higher than payments in many other disability categories.

This consolidation should lead to an end to some of the confusion blind persons have experienced when attempting to access Medicaid-related services, i.e. reduced rates from Boston Edison. Since the lists of recipients for SSI, blind and other SSI recipients have been maintained separately, it has often appeared to companies that blind clients do not receive SSI.

The Governor's plan requires a redetermination of approximately 15,000 SSI recipients when the DTA is established. As we learned under President Reagan's SSI redetermination policies, this could lead not only to confusion but to many people being incorrectly dropped from the SSI rolls.

In 1998 the administration of SSI will be taken over by the state as opposed to the federal government. This will allow the state to determine eligibility and establish uniform standards across all disabilities.

This change would also permit the state to monitor client compliance with rehabilitation and treatment. This could lead to persons being determined ineligible for SSI on

the basis of disagreement with a treatment program that has been established without their personal input or an inability to follow a rehabilitation plan as scheduled by standard rules. Having leverage over an individual's SSI grant is a very powerful method of control.

Medicaid eligibility and administration will also be moved to the Department of Transitional Assistance. This should save administrative costs and ease the disbursement of Medicaid funds in the event that a federal Medigrant Block Grant Program is initiated. The plan does not specify how Medicaid transportation for blind clients will be handled.

Funds for Ferguson Industries would be managed by the Vocational and Employment Support account of the Department of Disability Services. Because this account handles all disabilities, there is a risk that Ferguson workshops might be combined with workshops from the Department of Mental Retardation. This could lead to the blurring of the identity of blind and mentally retarded clients. Obviously, each population has different training needs, capabilities and needs for accessible equipment.

Consolidation of workshop management could stifle the progress currently being made by Ferguson Industries. They are about to initiate a program in Cambridge to train medical transcribers. Further innovations of this type could be lost for lack of a dedicated driving force.

Services for blind children would be grouped with services for children with all other disabilities. This ignores the special complication involved with educating blind children as well as the specialized training required of their service workers.

Elderly blind clients would no longer be handled by the MCB. They would become clients of the Elder Services Department. This could easily lead to reduced attention to the special needs of blind elders in order to develop a standard service program.

Salaries for direct care workers in the private provider system earning under $20,000 would be increased by approximately 4 percent. This would make the total budget for these salaries $7,547,351, an increase of $56,725.

The blind community is concerned about potential problems which include loss of individual identity, loss of a single voice to advocate for the blind in state government, and lack of a single agency that would be accountable to the community.

Current MCB Line Items

4110-0001
Office of the Commissioner and Research Bureau
FY1996 Allocation: $710,923
House 1A: $727,891

4110-1000
Community Services Program
FY1996 Allocation: $2,400,154
House 1A: $232,731; includes salary upgrade for POS direct care workers: $56,725

4110-1010
Aid to Adult Blind
FY1996 Allocation: $8,702,093
House 1A: folded in with other disabilities in DDS, not earmarked

4110-1020
Determining Medical Eligibility for Medical Assistance Program
FY1996 Allocation: $379,556
This line will move to the Department of Medical Assistance.

4110-2000
Turning 22
FY1996 Allocation: $4,942,955
House 1A: $778,098

4110-3010
Vocational Rehabilitation
FY1996 Allocation: $1,125,094
House 1 A: $1,128,479

4110-4000
Administration of Ferguson Industries
FY1996 Allocation: $1,718,992
House 1A: $1,727,257
This funding will be moved to the Vocational and Employment Support account (4920-0010) in the Department of Disability Services.

House 1A also includes $7,622,351 in the Bureau of the Blind account (4920-0050), including $56,725 for POS worker salary increases

Introduction

The Governor's Reorganization Plan

The Governor's reorganization plan for state government, "The Government We Choose," was announced in conjunction with his budget, House 1 A. In order for this plan to become a reality, it must be approved by the legislature through a set of eight Article 87 constitutional changes, thirty legislative bills and several outside sections of the budget. The particular bill regarding the reorganization of health and human services is HB 5804, Reorganization Plan Number Four.

Structure

In his plan, Governor Weld has redesigned the current system of agencies into consolidated secretariats. Each of the secretariats is divided into departments which are then subdivided into accounts and bureaus.

In this guidebook we will discuss only the Department of Disability Services and the Department of Public Health, both found in the Secretariat of Family Services. These are the two departments which encompass almost all services related to persons with disabilities. We have listed services according to the departments as they exist now.

The exception is the Architectural Access Board, which is consolidated in the proposed Department of Licensing and Regulation, under the Executive Office for Administration and Finance.

In the Governor's plan, the Secretariat of Family Services would be subdivided into five agencies: Disability Services, Public Health Services, Juvenile Justice, Children's Services, and Transitional Assistance. The Department of Disability Services would encompass the present Mass. Commission for the Blind (MCB), Mass. Rehabilitation Commission (MRC), Mass. Commission for the Deaf and Hard of Hearing and the Department of Mental Retardation (DMR). The Department of Public Health Services would include the present Department of Mental Health (DMH).

The secretariats would serve as purchasers rather than providers of service. This means that rather than providing services through state-contracted employees, the secretariat would sub-contract with independent providers. This is supposed to increase quality and decrease cost by introducing the competition of the open market. "Essential details such as how individuals would access services, how the quality of services are monitored, and the principles which would underpin services are missing. In fact economists agree that without safeguards, reliance on markets will result in inequities." (Leo Sarkissian, Executive Director, ARC Mass)

Through a system of contract-bidding, the secretariats would select providers as necessary. This proposal gives rise to the fear that contractors

will decrease quality and underestimate their costs in order to submit the lowest bid.

As a protection against this eventuality, the Governor ensures that contracts will not be renewed for providers who are found inadequate, and that clients will have the ability to change services which do not meet their needs.

This guarantee leads to several questions: Who will establish the criteria for "quality care"? How long will it take for a client to change providers, and what does he do in the meantime? What if no other service provider is available? What if there is a disagreement between the client and the case manager as to whether or not the client's needs are being fulfilled?

The Governor claims that by combining departments he would achieve a tremendous cost saving to the tax-payer. However, legislative and other critics have expressed serious doubts as to both the fundamental reality of this savings and the real cost in terms of human lives and dignity.

Single point of entry

One area of cost saving is to come from the development of a single point of client entry to the Secretariat of Family Services, and the maintenance of one coordinated data base. Indeed, this should produce greater efficiency by reducing layers of bureaucracy, simplifying the approval process for multiple services and providing a consistent resource base for each client. This should eliminate some of the duplication in administrative services.

If a client enters the secretariat at one single point, however, what is the next step in his case management? Will the file be handed to the first available case worker, who will then manage the case from that point on? This would mean that case managers would be required to be familiar with all of the individual needs of persons with all disabilities, as well as the myriad services available to them.

Case managers in the current system are often unfamiliar with the specific needs of an individual and the options available to him. The proposed restructuring requires already overburdened case managers to take on a monumental task.

In order to coordinate services for each person served in this new single point of entry system, the Governor proposes to assign one client identification number to each consumer. This could jeopardize confidentiality. For example, someone receiving adult living skills training may not want her case worker to know that she is seeking protection from spousal abuse.

Another problem is that of dual diagnosis. In the present system, dual diagnosis often leads to confusion, and clients can fall through the cracks between services. This is a particular problem for those who have a diagnosis of mental illness in combination with some physical disability or mental retardation. In spite of the service consolidations proposed by the Governor, these clients would be served by both the Department of Disability Services and the Department of Public Health.

Finally, a single point of entry would need to be accessible to people who are Deaf or hard of hearing, and those whose primary language is not English. This means that "1-800" access numbers should be hooked up to TTYs, and all case workers would need to learn how to use them. (A TTY — or TDD, as it is sometimes called — is a modem attached to a keyboard which allows anyone who is unable to use a telephone to type messages to others, via the telephone lines, who also have TTYs.)

Case workers would also need to understand American Sign Language and other communica-

tion methods commonly used by those who are Deaf or hard of hearing. At the very least, a staff of sign language interpreters at each area office would ensure accessibility to Deaf consumers.

Consolidation and competition

The total budget for the proposed Secretariat of Family Services is $7.2 billion. Each Department would be allocated a certain share of this amount, to be distributed among its accounts and bureaus.

As part of the consolidation effort,the Governor would create common boundaries for service regions in the state. 66 local offices would be reduced to 26, including one main office, 5 regional offices (to be located within area offices) and 25 area offices. This cutback could severely limit convenient access to service for clients in many parts of the state.

In order to estimate a budget for his new departments, the Governor has looked at the maintenance budget for current agencies, then added and subtracted amounts which he feels would be changed with restructuring.

Although figures from former departments have been used to calculate the amount needed by the new departments, this total provided only a basis for an estimate. None of the money in the new departments would be allocated for a specific population of clients.

This situation could easily lead to rivalries among disabilities advocacy and support groups. By forcing populations with different disabilities and therefore different needs to fight for a share of an ever-decreasing pot of money, the Governor will encourage divisions between us which will decrease our power. Therefore it is critical that people with disabilities and their allies join forces as a united front to maintain quality of care.

Weld's assumptions

The Governor relies for many of his promised savings on events which may not actually occur. To begin with, he assumes substantial increases in grants from the federal government as well as passage of the proposed Medigrant program. Under this program, states would be allocated block grants for Medicaid reimbursement which they could then spend in whatever ways they deemed appropriate.

The Governor also assumes unrealistic cost savings from administrative consolidation. Most observers predict that although state administration could be reduced through contracting-out of services and single point of entry for clients, this would involve a long and laborious process with administration never becoming quite as small as desired.

Another assumption is that public facilities such as state schools will be able to make a significant contribution to their own budgets ($30 million from DMH, DMR and DPH). This assumption is based on the hope that these facilities will find some way to generate revenue, becoming "public enterprises" — a term suggested by the Governor but only vaguely defined. Outside Section 36 of the Governor's budget sets up enterprise funds for these new entities. No revenue may be generated, however, without legislative approval.

Investigations

Investigations into alleged fraud and misconduct by Family Services departments would be conducted by the Office of the Secretary. This division would perform functions now provided by the Disabled Persons Protection Commission, MRC, Office for Children, and investigatory units in Public Safety, DMR and DMH.

We must ask ourselves, how willing will the

secretariat's administrators be to expose problems that will cost it additional funds? How willing will they be to uncover errors that they themselves have made in selecting a provider?

The Secretary's investigatory bureau would not only explore misconduct in the provision of disability services, but would also investigate welfare fraud. Since welfare fraud is a revenue-generating pursuit for the state and the discovery of abusive situations generally costs additional funds, the new bureau might be tempted to use more and more of its resources in pursuing welfare fraud rather than abuse of people with disabilities.

Raises

A bright spot in the plan is that salaries for direct care workers in the private vendor system (those earning under $20,000) would be increased by approximately four per cent. There has been no cost-of-living increase to private providers' state contracts in nine years, so wages in the system have stagnated at a very low level. Low salaries have led to high worker turnover, which has hurt the quality of service for service clients.

Consumer Input, Consumer Needs

John Winske, Executive Director of the Massachusetts Coalition of Citizens with Disabilities, is concerned because the Governor consolidates a wide range of services for a population of diverse needs into a few line items. "We are not cookie cutters," he explains. "You cannot lump us together. The needs of an institutionalized person are not the same as those of a person living in the community who uses a wheelchair, of a Deaf person, or someone who was in an automobile accident. We don't all fit in a neat package."

A member of the Board of Directors at the Northeast Independent Living program warns, "...the plan proposed by the Governor will have an homogenizing effect that will strip us of our unique differences and needs, with disastrous results down the line."

A 1990 publication, "Creating Open Communities," based on years of community input, emphasized three principles for ensuring effective services for people with disabilities:

1. Responsive, consumer-focused points of entry are important to provide equal services for all. Information and referral networks require well-trained staff.

2. System-wide disability policy has to ensure cross-disability awareness, with consumer input, in order for consumers to receive effective access to transportation, civil rights, housing, and many other areas.

3. Comprehensive data collection should prevent unmet service needs from occurring. An efficient, up-to-date system can help agencies plan for the future.

Any changes to the current functions of line items, or to the structure of secretariats, need to be carefully thought out.

In its testimony before the Joint Committee on Human Services and Elderly Affairs on February 13, the Cape Organization for Rights of the Disabled stated, "The proposal...must not be revived until the voices of those served are heard and a truly honest assessment of what does and what does not work in state government is made."

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Architectural Access Board (AAB)

The Architectural Access Board enforces state and federal regulations designed to make public buildings accessible to people with disabilities. The AAB staff also offers limited assistance in answering access questions. Presently, the AAB is an independent agency of the Executive Office of Public Safety.

The Governor's reorganization plan consolidates the functions of the AAB in the Department of Licensing and Regulation, under the Executive Office for Administration and Finance. This is the only disability-related regulatory agency located outside of the proposed Executive Office of Family Services. According to a reliable source, this plan makes sense, since it retains the AAB's current functions without compromising its ability to effectively enforce such laws as the Americans with Disabilities Act.

The federal Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in nearly all segments of society. Title I of the Act covers employment; Title II covers state and local government services, including public transportation; Title III covers public accommodations, commercial facilities, and specified private transportation; Title IV covers telecommunication; and Title V contains miscellaneous provisions, including coverage of Congress.

Line item for AAB:

8000-0500 Architectural Access Board
FY1996 allocation: $186,669

Department of Disability Services (DDS)

The Department of Disability Services is one of the five departments in the new Secretariat of Family Services. It would combine the present Massachusetts Commission for the Blind, the Department of Mental Retardation, the Massachusetts Rehabilitation Commission and the Commission for the Deaf and Hard of Hearing.

The mission of DDS is to maximize quality of life. For many, this cannot be achieved without respect for their own participation in the design of their service plan, the dignity of being considered a person with individual needs, and some type of employment.

The goals of this department are: to provide intensive family and individual support; to keep families intact and reduce residential placements; to provide vocational rehabilitation and employment for individuals; to return people currently in institutions back into the community; and to provide people with the technology they need for maximum independence, i.e., talking computers for the blind.

While these are lofty and desirable goals, it is not simply a matter of administrative inefficiency that they are currently not being addressed. Waiting lists for services exist in every department, and funding for those services is exhausted before the end of the fiscal year. The Governor does not propose additional funding to address unmet needs; in fact, if his savings assumptions do not materialize from the reorganization, services might have to be cut to compensate.

This plan also does not address the reality of a lengthy transitional phase which would be necessary in order to get this new system up and running. Persons with disabilities do not have the luxury of waiting until tomorrow in order to have their lives progress. Confusion, lack of available community services and even longer waiting lists (even if they are neatly consolidated in one file) are not a pleasant thought.

The budget for this department would be $793,785,532. While the former agencies had a total of 8,517 full time employees, the Governor plans to reduce this number to less than 8,276 by the end of Fiscal Year 1997. His plan does not mention where these laid off employees will find jobs or any plans for re-training them.

Once the former departments have been consolidated, the Department of Disability Services would be broken down into four accounts and two bureaus: Family and Individual Supports; Vocational and Employment Support; Residential Supports; Program Management and Operations; and Bureaus of the Blind and of the Deaf and Hard of Hearing.

Line items for DDS in House 1A:
4920-0000
Residential Supports: $551,023,069
Includes: shared living support and 24 hour residential care in both community and institutional settings.
$4,705,438 is for a salary increase for direct care workers earning under $20,000. $19,131,564 of the total may be transferred to line item 4910-0330 in DPH for the purchase of state employee health benefits.

4920-0010
Vocational and Employment Supports: $117,452,776
This account provides funding for vocational rehabilitation and employment assistance. The goal is to lead the client to economic self-sufficiency. This ignores the hundreds of persons with disabilities who may never become economically independent but who nonetheless have skills and talents which can be used in a productive way.
Counseling and auxiliary services in this account are provided by the state. All other services are obtained through contracts with private vendors or vouchers.
Employment supports include sheltered workshops, work crews, provider owned service volunteers, workers paid by providers, employer support, and competitive employment.
This account also funds:
Vocational rehabilitation: counseling and placement to find work.
Educational and training support: day activities for people who need serious support.
Transportation: travel to work, training, day care, leisure activities.
Auxiliary aids and services: devices and services for independence, such as adaptive equipment, orientation and mobility, interpreters, rehabilitation, and PCAs.
Ferguson Industries for the blind are also managed in this account
$1,275,633 is for an increase in salary for direct care workers in the private provider system.

4920-0020
Family and Individual Supports: $76,584,828
This account provides flexible supports for families and individuals including those with elder care givers at risk, independent living supports, home care assistance personal care attendants, clinical teams, emergency residences, alternative day supports, and auxiliary aids and services.
$251,645 is for a salary increase for direct care workers in the private provider system.

Deaf-Blind services: $3,500,484

4920-0030
Program Management and Operations: $38,988,084
This includes policy and program development, intake and referral and quality assurance.

4920-0040
Bureau of the Deaf and Hard of Hearing: $2,189,424
$12,526 is for salary increase for direct care workers.

4920-0050
Bureau of the Blind: $7,547,351
$56,725 is for salary increase for direct care workers.

4920-0035
Interpreter Services, Retained revenue: $70,000

Department Of Transitional Assistance (DTA)

Past Weld budget proposals have taken a slash-and-burn approach to the welfare department, now called the Department of Transitional Assistance. Some of the Governor's major cut-backs of benefits to low-income people were first proposed or re-proposed in his budget submission, House 1: for example, tightened eligibility for Emergency Assistance homelessness prevention; the elimination of General Relief; and his infamous welfare reform bill. This history makes the FY97 proposal (House 1A, or H1A) surprising. For some reason, whether he's being strategic in his run for national office or he's simply already done what he wanted to do, Governor Weld proposes no new sweeping changes in DTA.

This is not to say that all is rosy with H1A's DTA proposal. One repeat proposal is to restrict over half the people with disabilities assisted by Mass. Rehab. vocational services to one year of automatic eligibility for **Emergency Aid to Elders, Disabled, and Children (EAEDC)**. These individuals have been determined to be severely disabled under Mass. Rehab. Commission criteria and are participating full-time in vocational rehabilitation programs. H1A would require them to reestablish their disability after one year under different disability rules, which would funnel more money to a for-profit company, Health Pro, for these case reviews. The Administration projects that over 700 people with disabilities will lose EAEDC benefits as a result.

In addition, the Governor proposes cutting off EAEDC benefits to any recipient with disabilities who has a substance abuse problem or whose disability is based in whole or in part on past substance abuse, such as people with AIDS from past intravenous drug use or with liver disease from past alcoholism. The Administration's motivation stems from the fact that similar restrictions to SSI have been proposed in Congress and will be again; this language would prevent people cut off SSI from applying for EAEDC instead. The specter of able-bodied addicts getting government checks to fund their habits isn't based in fact; current EAEDC disability rules require proof of some other disability besides substance abuse to qualify, and DTA has the authority to put recipients on vendor payments (checks directly to landlords) in any situations where there is mismanagement of funds. Advocates are alarmed at the prospect of hundreds of people with severe disabilities in detox or drug treatment programs becoming homeless if DTA eliminates their ability to pay their rent and utilities.

In contrast to this "circle the wagons" approach to federal cuts to sub-

stance abusers with disabilities, there is a forward-looking proposal to set aside funds for 15,000 elderly and disabled legal immigrants to get benefits from the state if the federal government cuts them off SSI - as, for example, the welfare bill vetoed by President Clinton in December would have done. This kind of planning ahead for the most likely federal cuts should be commended by advocates and repeated by the legislature. (The welfare proposal currently under debate, the National Governors' Association plan, does not include any cuts specific to immigrants.)

In the past, the state has spent up to $2.1 million a year assisting EAEDC recipients applying for SSI, which both helped recipients get higher benefits and saved the state money by shifting people to a primarily federal program; this effort is virtually eliminated in H1A by cutting the funding down to $200,000. Health coverage for EAEDC recipients is moved from DTA over to the new Department of Public Health Services.

EAEDC and SSI are merged into one line item, which could signal policy changes down the road, possibly merging the programs eventually. There appears to be enough money in this account to cover everyone eligible. The department is directed to draft a plan to take over running the SSI state supplements by October 31, 1996. This reflects the state's resentment at last year's federal decision to charge the state a fee for processing the supplements, a resentment DTA promptly took out on recipients by subtracting half the fee from their SSI checks despite the legislature's rejection last year of such a $5/month benefit cut.

The department is also directed to seek federal permission for the state to conduct redeterminations of disabled people's eligibility for SSI, which currently only the federal SSA is allowed to do. The state has been critical of the federal government for falling behind in the periodic redeterminations prescribed by SSA regulations. Advocates have no problem with more redeterminations being conducted, but question whether the real motivation is to create excuses to cut people off and to give a private contractor the financial incentive to deny benefits to as many people as possible.

Department of Mental Health (DMH)

The current Department of Mental Health would now be found in the Secretariat of Family Services under the Department of Public Health. It would be combined there with the former Department of Public Health, the Department of Medical Assistance, the Department of Medical Services and the Rate Setting Commission.

It would be easy for the former DMH to lose its identity in the new system, placing at risk attention to specialized needs, funding mandated for specific services and a distinct voice in state government. Says Barbara Cantrill, Director of the Alliance for the Mentally Ill, "We do not approve of any moves that consolidate the Department of Mental Health's operations or administration with any other human service departments as this would only dilute responsibility for the care of the seriously mentally ill."

The fact that the Department of Mental Health has been isolated from other disability services has subtle implications. Does it perhaps indicate that mental health care should be simply a matter of crisis prevention through public awareness and education, while other disabilities require ongoing services and treatment? Is mental illness only a temporary crisis that can be addressed in an acute care setting and then turned over to an inadequate system of sporadic community care?

The new plan would consolidate the 12 current DMH line items into four new line items under DPH. This would reflect a net reduction in the former DMH line items of $6.1 million. The new line items would form a general pool of money for all services under the new Department of Public Health Services. None of this money would be specifically earmarked for mental health services.

The saving to the state is supposed to come largely from administrative cost savings as a result of combining several agencies under the new Department of Public Health Services. Administration includes management and budget, program operations and policy and planning.

Mental health would benefit from the fact that the Governor has recommended a $1 million expansion for services for homeless mentally ill and $3 million to expand continuing care services in the community. This should serve to reduce the waiting list for an ever increasing population.

There will be some expansion and annualization of funding for DMH in the new plan, including:

- Metro-Boston deficiency funding of $5.5 million
- Child and adolescent ESIS physician and nurse on call respite, $0.535 million
- Collaborative assessment, $0.535 million

• Forensic expansion, $0.545 million
• Salary increase for POS direct care workers earning under $20,000, $2.877 million

DMH stands to lose $1.5 million when abuse investigations are moved to the Executive Office of Family Services. Most licensing will be moved to the Executive Office of Administration and Finance; DMH licensing will not.

Other DMH budget reductions would include:
• Transfer of 5 DMH clients to DMR, $0.273 million
• Outpatient savings of $4 million. (The Governor plans to save this money by consolidated purchase of outpatient services by DMA and DMH. If block grants are not passed, then individuals would lose service if the state does not restore funding.)

Some $3 million has been allocated for the Annie Casey Initiative which funds services for children under three years of age. However, this money is dependent upon receipt of the Annie Casey Foundation Implementation grant. This money is now found in both line items for Purchased Medical and Support Services, Ambulatory and Acute (Line item 4910-0300), as well as Continuing Care (Line item 4910-0310).

Under reorganization, the Secretariat of Family Services is ordered to design a plan to create public enterprise systems within current facilities (including DMH). Although no specifics have been described as to the structure of these enterprises, the Governor has already assumed an $11.5 million savings from contributions from former DMH facilities. This amount accounts for 7% of the current DMH budget.

The cost of insurance for all facility workers would be covered by the new Department of Public Health Services. The state presently pays 85% of this insurance, but this would drop to 75% under the new plan. The Governor has proposed increasing the workers' share of insurance costs before, and the legislature has always refused to go along with it. This funding would cover the cost for 2,948 workers at the 75% rate.

Line Items for DMH

5011-1000
Administration for DMH
FY1996 Allocation: $19,596,182
House 1A: $16,457,339. This represents a decrease of $2,920,054.

5042-1000
Operation of Medfield State Hospital
FY1996 Allocation; $1,487,801
House 1A: $1,523,998

5042-5000
Child and adolescent services
$69,408 of this money is for Franklin Community Action Corp. in Greenfield for its youth and adolescent services program.
$25,000 of this money is for sending children to summer programs funded by DMH.
FY1996 Allocation: $56,451,054
House 1A: $57,719,000

5046-0000
Adult mental health and support services
$50,000 of this money is for comprehensive rehabilitation services provided for the mentally ill homeless . These will be provided through the Multiservice Center in Lynn by a vocational rehab agency specializing in employment for mentally ill adults.
$163,000 of this money is for western Mass. community enterprise programs.
$68,140 is for Ad-Lib Inc. in Pittsfield.
Language in the FY96 budget prevents the closing of Solomon Carter-Fuller Mental Health Center or Mass. Mental Health Center.
This line item was increased by $5.5 million for

supplemental funding earmarked for the Metro-Boston deficiency.
$3,642,535 will be added to this line from Medicaid receipts for mental health centers from the federal government.
$272,784 will be removed from this line due to the transfer of 5 DMH clients to DMR.
$735,580 will be lost from transfer of investigators to the Executive Office of Family Services.
FY1996 allocation: $228,257,106
House 1A: $243,052,672
$1 million has been added to this line for services to the homeless mentally ill; $3 million has been added for enhancement of continuing care.
There has been an increase of $2,876,718 to cover 4% salary increase for direct care workers.
$4 million would be lost for outpatient services. The Governor plans to save this money by consolidated purchase of outpatient services by DMA and DMH. If block grants are not passed, individuals would lose service if state does not restore funding.

5046-1000
Rental subsidies to eligible clients
FY1996 Allocation: $2,607,550
House 1A: $2,607,550

5046-2000
Homeless services
$180,000 of this money is for Project AIM of Community Enterprises of Berkshire County for people with dual diagnosis of major mental illness and substance abuse and who are homeless or at risk.
FY1996 allocation: $8 million
House 1A: $8 million (Note: $1 million added to homeless services under line 5046-0000.)

5046-3000
for Metro-Boston homeless prevention
FY1996 Allocation: $6,095,000
House 1A: $6,095,000

5046-4000
Authorizes DMH to spend up to $125,000 collected from occupancy fees charged to tenants in creative housing option in community environments, the CHOICE program. This money is for routine maintenance and repair and personnel.
FY1996 Allocation: $125,000
House 1A: $125,000

5046-9999
Insurance costs
FY1996 allocation: $10,354,776
House 1A: $17,890,778

5051-0100
Community mental health centers
FY96 language prevents the closing of Dr. Harry Solomon Mental Health Center, Dr. John C. Corrigan Mental Health Center and Erich Lindemann Mental Health Center.
FY1996 allocation: $77,523,513
House 1A: $75,361,888
$1.5 million reduction from assumed savings from public enterprise initiative.
Reduce $1,334,112 for administrative efficiency. This means cutting 32 full time employees.

5055-0000
Forensic services
FY1996 Allocation: $7,047,659
House 1A: $7,669,498

5095-0000
Adult inpatient and facility services
FY96 budget language prevents the closing of Worcester State Hospital, Westboro State Hospital and Medfield State Hospital.
FY1996 Allocation; $101,369,729
House 1A: $90,800,635
Reduction of $1,834,404 from administration.
$10 million assumed savings from public enterprise initiative.

Department of Mental Retardation (DMR)

The current Department of Mental Retardation would no longer stand as an independent agency. It would be relocated to the Secretariat of Family Services under the Department of Disability Services. The department would be administered in conjunction with the present Massachusetts Commission for the Blind, the Commission for the Deaf and Hard of Hearing, and the Massachusetts Rehabilitation Commission.

By grouping mentally retarded clients with other people with disabilities, one runs the risk of ignoring the special needs of this unique population. If eligibility and performance criteria are standardized in the new department, mentally ill clients will not fit into generally assigned categories.

Another difficulty with the plan is its goal of self-sufficiency for clients. Some people will need ongoing service support. "Mental retardation is a medical diagnosis for which there is no cure. Time limits are not appropriate for persons using mental retardation-related services. The plan assumes that persons with mental retardation 'get better,' and leave the system. They do not." (Leo Sarkissian, Executive Director, ARC Mass)

The former DMR will be forced to share a general pot of money when it is moved to DDS. As a vulnerable population with critical and specific needs, it is important that mentally retarded clients retain their own identity. This would also assure them of a dedicated spokesperson in state government and a separate voice on disability issues.

No mention is made of addressing the current waiting list of over 4,000 persons. These people have been waiting a long time for services, primarily residential and employment.

The Governor proposes to move forward in his plan to reduce the number of institutional placements and turn to community care. While small group homes and community residences are certainly preferable to large and costly institutions, we must make sure that adequate support is available within the community before any doors are closed.

It is ironic that many family members are fearful that community services for their loved ones
will not be available in the community, therefore clinging to institutional placement. This could be the regressive next step taken by many families if institutions are the only place to find sufficient care.

The Governor is assuming a large cost savings from a public enterprise initiative. This would hold public facilities, such as state schools, responsible for contributing a significant share of their own funding. While the plan does not detail a system for this transition, it sounds quite impractical on the surface.

The new line items make no provision for service coordination between residential and vocational services. This is essential for many DMR clients who are not independent enough to manage the two issues separately.

Investigations of fraud and abuse would be taken from DMR and placed in the new Executive Office of Family Services. There they would compete with investigation of charges against all other disability services as well as welfare fraud.

This situation could lead to a struggle for scarce dollars to pursue abuse charges. We predict that welfare fraud investigation, a revenue producer, would receive the bulk of the money.

An additional $4 million would be given for services to unserved elders. These are clients who are living with aging care-givers who are no longer able to fully care for them. The funds would assist the client to remain in the community for as long as possible.

The Turning 22 Program would receive its usual allotment of $4.4 million. While this would serve 160 people, approximately 450 clients are added to this list annually. The net result is an addition of 300 clients added to the current waiting list.

It should be specified in the plan that careful monitoring, reevaluation of client service plans and a department policy review will take place on a regular basis. This would help to maintain standards on a consistent level.

Line Items for DMR

5911-1000
Administration of DMR
FY1996 Allocation: $5,356,480
House 1A: $5,473,127

5911-2000
Transportation for adult services
FY1996 Allocation: $24,967,470
House 1A: $24,968,287

5911-9999
Employee insurance
FY1996 allocation: $14,860,475
House 1A: $14,860,475

5920-1000
Administration and Program Support of Adult Services Program
FY1996 Allocation: $28,980,702
House 1A: $30,503,344

5920-2000
Community based residential adult services
FY1996 Allocation: $243,224,019
House 1A: $250,202,241; includes Purchase of Service (POS, private vendor system) direct care worker salary upgrade of $4,705,438; also includes $2 million to expand services to older people previously unserved.

5920-2010
State operated community based residential services for adults
FY1996 Allocation: $41,709,392
House 1A: $43,534,110

5920-2025
Community based day and work programs for adults
$65,000 of this money is for alternative work program at Life Focus center in Charlestown
FY1996 Allocation: $67,296,823
House 1A: $68,528,156, including salary upgrade for POS direct care workers of $1,231,333

5920-2040
Community based health services for adults
FY1996 Allocation: $10,976,334
House 1A: $11,454,491

5920-3000
Respite services
1996 Allocation: $34,161,929
Salary upgrade for direct care workers: $222,493
House 1A: $36,384,422

5920-5000
Turning 22 Program
This will serve a maximum of 160 clients. $8.5 million of this money is allocated to maintain services for priority 1 turning 22 clients who began receiving services in FY96.
FY1996 Allocation: $4,400,000
House 1A: $12,900,000

5920-6000
Services to older unserved
$2 million of this money is for clients who remain at home
FY1996 Allocation: $4,750,000
House 1A: $4,750,000

5920-8000
Child and adolescent services
FY1996 allocation: $2,836,077; $437,000 of this money is for families with autistic children.
House 1A: $2,836,077
The Governor's plan does not specify funds for autistic children.

5920-8010
Residential expense for school placement of children and adolescents between ages of 4 and 21
FY1996 allocation: $700,000
House 1A: $700,000

5930-1000
Facility operations
FY1996 allocation; $232,009,169; language prevents closing of Paul A. Dever State School, Hogan Regional Center and Wrentham State School
House 1A: $257,517,917

5930-2000
Maintenance and operation of Glavin Regional Center
FY1996 Allocation; $5,704,021
House 1A: $5,908,007

Disabled Persons Protection Commission (DPPC)

The Disabled Persons Protection Commission investigates reports of abuse of adults with disabilities ages 18-59 in institutional, community, and private home settings. The Commission also assigns and oversees abuse investigations performed by the Mass. Rehabilitation Commission, the Department of Mental Health, and the Department of Mental Retardation.

DPPC itself conducts approximately 260 investigations per year. Currently 60 are open cases; also open are one Commissioner's investigation and 11 retaliation cases. There is no waiting list for investigations.

Under the reorganization plan, the Disabled Persons Protection Commission is eliminated as a stand-alone agency. Instead, the investigative responsibilities of the DPPC, together with the investigative functions of the Mass. Rehabilitation Commission, the Department of Mental Retardation, and the Department of Mental Health investigations units, the Office for Children's child care investigations, and welfare fraud investigations are all transferred to the proposed investigations unit within the Executive Office of Family Services.

Disability advocates have several objections to the Governor's proposal. First, this creates a tremendous burden on one investigatory unit. Advocates question whether abuse of individuals and abuse of the welfare system make a good organizational match, since more attention is likely to be paid to welfare and vendor fraud, which are revenue enhancing.

Advocates are also concerned that there might be a lack of objectivity in investigations conducted by and within the same Secretariat; political and budgetary concerns could interfere with the the new agency's ability to pursue independent investigations of DMR and DMH facilities or state funded vendor agencies.

In sum, combining the DPPC with other investigatory agencies within a family services secretariat would end its independence and would compromise the legislature's intent when it established this agency.

Line item for DPPC:

1107-2501 Disabled Persons Protection Commission
FY1996 allocation: $1,363,335

Massachusetts Office on Disability (MOD)

The Massachusetts Office on Disability was created in 1981 as the Office for Handicapped Affairs, an independent agency within the Executive Office for Administration and Finance. MOD's mission is to *"...bring about full and equal participation of people with disabilities in all aspects of life...in a manner which fosters dignity and self determination."*

Through the **Client Services Program**, the **Community Services Program**, and the **Government Services Program**, MOD serves as both advocate and technical advisor to individuals with disabilities who have faced discrimination or who are not receiving services for which they are entitled; advises communities, private businesses and organizations as they begin to comply with state and federal access laws such as the federal Americans with Disabilities Act of 1990 (ADA); and monitors the state government's ADA compliance.

The Governor's reorganization plan eliminates the Massachusetts Office on Disability as a separate agency. According to the Governor's Office, the monitoring responsibilities of MOD would be transferred to the Office of the Secretary of Family Services, which consolidates the state's investigative functions, including welfare fraud and the Disabled Persons Protection Commission. Since it is more profitable for the state to investigate fraud than it is to monitor its obligations to comply with disability laws, advocates and consumers fear that MOD's scope will be limited, and its effectiveness diminished.

Each year, the **Client Services Program** assists 5000 people with disabilities to receive the services for which they are entitled, such as vocational rehabilitation, independent living, housing, transportation, architectural and communication access, and public education. This program is the result of a federal Client Assistance Program grant.

Since MOD would be subsumed by the new Family Services Secretariat, rather than retaining its current stand-alone status, millions of dollars in federal vocational rehabilitation funds would be lost. In its testimony during hearings on February 13, the Cape Organization for Rights of the Disabled stated that eliminating MOD will leave thousands of people and the cause of equal access "...high and dry...This compromises the independence of the program and thus *seriously* jeopardizes $45 million in federal vocational rehabilitation and independent living funds coming to Massachusetts, according to the federal Rehabilitation Services Administration."

In order to strengthen public awareness of state and federal access laws, MOD's **Community Services Program** has trained over 8,000 volunteers

to be Community Access Monitors. This program also helped establish 170 municipal Commissions of Disabilities to provide communities with local expertise on issues of importance to people with disabilities. In addition, this program works with cities and towns on their ADA responsibilities. MOD receives over 10,000 calls each year from municipalities, private businesses, non-profit organizations, and individuals who have compliance questions about state and federal access laws.

For the last several years, MOD has been awarded the Disability and Business Technical Assistance Center grant by the U.S. Department of Justice. Awards are based on knowledge of the ADA and of the state's disability community. However, since the Secretary of Family Services would be a new entity with no identifiable track record on ADA, future funding from this source would be difficult to obtain.

Under the **Government Services Program,** MOD serves as the ADA coordinator for state government. MOD is regularly called on to assist agencies to remove existing structural, communication, and operational barriers. For example, MOD has been working with the State House Project Office to remove architectural and communication barriers; actual improvements are slated to begin during 1996.

As is the case with other investigative units consolidated under the Secretariat of Family Services, "the fox would be watching the hen house," removing incentives for the state to comply with access laws. Although the Governor's office says the state is committed to administering the functions of MOD for FY97, it makes no guarantees that MOD's responsibilities would continue in FY98.

Line item for MOD:

1107-2400 Massachusetts Office on Disability
FY1996 allocation: $525,246

Massachusetts Commission For The Deaf And Hard Of Hearing (MCDHH)

In recognition of the special communication access needs of people with hearing loss, the Massachusetts Commission for the Deaf and Hard of Hearing has been coordinating services for Deaf/deaf, late-deafened deaf, and hard of hearing people throughout the Commonwealth, since its inception in 1986.

Currently, there are about 40,000 Deaf residents, 10,000 of whom lost their hearing before age 19. In addition, about 302,000 people are hard of hearing, of whom 146,000 have substantial hearing loss.

Categorizing people with hearing loss is extremely difficult, since the degree of hearing loss is often blurred, as are the varied needs of every individual. Keeping this in mind, two groups exist: one group considers deafness to be their cultural identity rather than a disability (the big "D" Deaf), whose primary language is American Sign Language, a separate and distinct language from English. The other group includes those who prefer to communicate primarily through whatever residual hearing remains (small "d" deaf), aided by such supports as lip-reading, hearing aids, and assistive technology such as Computer Aided Realtime Technology (CART) services. This group, which includes some late-deafened and many hard of hearing individuals, prefers English as its language base. However, one must be careful when making such distinctions, as there is a great deal of crossover between individual preference and need among those with this invisible disability.

In testimony before the Joint Committee on Human Services and Elderly Affairs last February 13, the Massachusetts Registry of Interpreters for the Deaf (RID), whose 300 members work to ensure that effective communication is available for people with hearing loss, emphasized, "Massachusetts has been a leader in the nation in the provision of services to Deaf and hard of hearing people. We have had an integrated statewide services delivery system that provides not only interpreter services, but case management and communication access, as well."

Services presently offered by MCDHH are as follows:

The **Commissioner's Office** monitors the effects of legislation on Deaf and hard of hearing consumers, and ensures that awareness of communication access issues exist in the legislative process.

The Commission's **Department of Case Management** provides services to Deaf and hard of hearing people with complex needs by using bilingual case managers. Here, client-related referral services, cross-agency

case coordination and technical assistance to state and community agencies takes place.

The **Department of Interpreter Services** maintains and coordinates statewide sign-language and interpreter referral services, as well as CART referral services.

The Governor's plan contains a $200,000 increase for six additional interpreters. However, the Massachusetts Registry warned, "...this amount is not enough to significantly meet the demand that currently exists."

RID explains, "The single greatest issue facing our field today is a chronic shortage of skilled, qualified interpreters....In the most recent fiscal year, the Commission was unable to fill 40% of requests received for interpreting services. ... [The Commission] has a budget that falls far short of the amount necessary to serve its clientele."

RID also is concerned that the quality of interpreter services may be compromised, if services for Deaf people are consolidated with those of other populations: "The proposal states that the Department of Disability Services...will be responsible for interpreter screening. ...Given the pressing demand for service, we fear that standards will be lowered to increase the supply of interpreters."

Since the Commission's establishment, the demand for interpreters has escalated dramatically.

The **Department for Communication Access, Training and Technology Services** provides public education and private technical assistance and training to public and private agencies across the state.

MCDHH also provides funding to seven **independent living programs** across the state, where about 1000 consumers learn daily living skills such as money management, parenting skills, and training in assistive technology. These and other important services are provided in communication-accessible environments.

RID strongly objects to the Governor's reorganization plan, which proposes to consolidate services for this population with services for people who are blind, mentally retarded, and those with developmental disabilities under the Vocational and Employment Supports, Family and Individual Supports, and Program Management and Operations line items. In its testimony, the Registry warned, "Knowledgeable administrators and policy-makers (many of whom are Deaf themselves) are to be replaced by a behemoth of a bureaucracy that does not and can not understand the needs of this important constituency."

Although the Governor promises to deliver the same level of services that consumers now receive, the proposed consolidation of regional offices to include a multitude of citizens with a wide variety of disabilities concerns many who understand the complexities of hearing loss. Who will guarantee appropriate services? Will a "1-800" number be both voice and TTY accessible? Will the receptionist at each area office serving many types of disabilities be skilled in American Sign Language, understand how to use a TTY, and how to interpret a message not specifically written in an English format? Will the building be communication accessible as well as physically accessible?

Historically, people who become deaf later in life and individuals who are hard of hearing have been overlooked and have not received their fair share of services. Where would the resources be to meet the needs of those who are already underserved?

Tom Boudrow, Executive Director of the Massachusetts State Association of the Deaf, is

concerned that equal access would be lost for thousands of citizens if this plan is implemented: "If the Commission ... loses its status as a state commission, greater obstacles will exist for Deaf and hard of hearing people who are simply trying to open doors to equal opportunities and reach the same levels of achievement as hearing people."

Line items for MCDHH:

4125-0100, 101
Mass. Commission for the Deaf and Hard of Hearing
FY1996 allocation: $3,035,903

Massachusetts Developmental Disabilities Council (MDDC)

In the original version of House 1A the Massachusetts Developmental Disabilities Council was incorrectly placed in the Department of Disability Services. Federal statute mandates that it be located separate from other disability services in order to maintain its independent status. A new location for the MDDC has not yet been decided.

The money received by the MDDC is from two federal grants. With the current status of the federal budget not yet decided, it is unknown what the amounts for the MDDC grants will be this year.

MDDC Federal Grants

1100-1703
FY1996 Allocation; $1,230,296

1100-1710
FY1996 Allocation: $384,101

Medicaid

The most interesting Medicaid news in the Governor's budget isn't what's included but what's not included. In 1995, the Governor filed a waiver request with the federal government to change Medicaid eligibility rules, making more working people with disabilities or with children eligible and giving away most of the free care pool as employer tax credits. The waiver was approved by the feds but then not passed by the legislature. If the Governor were truly invested in these proposals, wouldn't he have re-proposed them in his budget, as he did with his welfare bill in 1994 and1995? But there's no sign of the waiver in H1A. No doubt the administration's reasoning is that the Medicaid program may be changed drastically any moment now by Congress, so there's no point in tinkering with the old program. This reasoning is flawed, because the most likely scenario is a block grant giving states more flexibility, and Massachusetts would be allowed to keep any eligibility expansions it had previously passed. While the employer tax credits for providing health benefits are an idea that deserved to be forgotten (they would drain the free care pool whether or not any currently uninsured people get insurance), we regret the lost opportunity to promote the expansions of Medicaid to more people with disabilities and more families with children.

Except for the prior year Medicaid payments, which retain their own account, the current Medicaid line items are lumped together with numerous Public Health, Mental Health, and other programs into two huge line items, Acute and Ambulatory Care and Chronic Care. This merging of entitlement programs with non-entitlement programs is a big problem for the other departments such as the Department of Public Health, but it's not particularly worrisome for Medicaid entitlement programs, like family coverage.

Within Medicaid, the non-entitlement programs that could possibly be drained if funds were needed for entitlement programs are **CommonHealth** (coverage for working people with disabilities) and the **Children's Medical Security Plan**; they should have their own line items. Of course, if federal standards for eligibility and minimum benefits are lost in a Medicaid block grant, then vigilance and pressure will be needed to protect *all* Medicaid coverage for people in Massachusetts.

Massachusetts Rehabilitation Commission (MRC)

The Massachusetts Rehabilitation Commission assists people with permanent disabilities to achieve maximum independence through such services as job training and placement, independent living services, and home care assistance.

Under the Governor's proposed reorganization, MRC would be consolidated under the Department of Disability Services, which would serve people with developmental disabilities, as well as those who are deaf and/or blind. MRC's services would be merged with those of the Department of Mental Retardation, the Mass. Commission for the Deaf and Hard of Hearing, and the Massachusetts Commission of the Blind into four new line items, entitled Vocational and Employment Supports, Family and Individual Supports, Community and Institutional Residential Supports, and Program Management and Operations.

A reliable source explains that it's hard to know whether MRC's clients would be compromised by the Governor's planned reorganization. For example, about seven home care administrators currently process clients from MRC's central offices for the entire state. Would these workers be placed in new area offices scattered across the state which serve a diversity of disabilities with a multitude of needs? If MRC consumers call a "1-800" number, could they be assured of receiving home care services?

In his testimony before the Joint Committee on Human Services and Elderly Affairs on February 13, 1996, William McCarriston, Jr., Executive Director of Community Work Services, the oldest vocational rehabilitation organization in the country, warned, "...the Commonwealth jeopardizes more than $40 million in Federal Vocational Rehabilitation funds to provide services. The federal regulations require a separate administrative structure for the Commission if federal funds are to be captured. Several years ago, the state of Florida attempted a similar reorganization, and when taken to court for their actions, had to reimburse the federal government significant sums of money."

McCarriston concluded, "The Americans with Disabilities Act clearly grants civil rights to persons with disabilities, and among those rights is the right to become self sufficient. The MRC is the vehicle for those rights. Clearly the Commission is functioning well. In the parlance of the street, 'If it ain't broke, don't fix it.'"

Vocational Rehabilitation

This account, which operates the state matching funds required by the federal vocational rehabilitation program, is available to all people with

physical or mental disabilities except those who are blind, who are served through the Mass. Commission for the Blind. Van and housing modification programs are also operated through this account.

Currently, there is a two-year waiting list for vehicle and home modifications. Each independent living center only receives an average of $10,000 for auxiliary supports, such as TTY's and signalers for Deaf mothers; over 100 consumers are waiting for these services.

Independent Living Services

MRC's turning 22 services, independent living services, protective services, and the new housing registry are included in this account.

Currently, MRC's **turning 22 residential services** uses $721,000 to meet the needs of 40 young people with serious physical disabilities who have made the transition out of the Massachusetts Hospital School in Canton and are now living in their own apartments. In addition, through **early intervention turning 22 services,** 50-60 students in such schools as Lexington's Cotting School are learning the skills they will need to live independently when they reach age 22 and are considered too old to receive services under special education laws. However, the Governor's reorganization plan fails to mention whether MRC's young clients will continue to receive these services.

Supported living services enable adults with severe disabilities to live more independently, rather than in nursing homes or other institutions. Currently, MRC serves 38 people in Boston and Taunton. MRC recently received a general grant for three years to expand the program for 20 people with disabilities who are considered homeless because they are living in institutions or residential schools. The Governor's reorganization plan fails to mention this important service.

During hearings before the Joint Committees of Human Services and Elderly Affairs, the Massachusetts chapter of the Association for Persons in Supported Employment recommended "...that state employment funds under line item 4920-0010 not be consolidated [and] ...that MRC service dollars remain within the designated unit..."

Protective services, which provide emergency placements or crisis intervention for people with disabilities who are at risk of abuse by their caregivers, presently operate with a staff of eight persons and a total budget of about $364,000. The Governor's proposal moves this service to the Executive Office of Family Services, where many other investigative and monitoring functions would be housed. Presently, protective services are administered in the independent living account to prevent clients at risk from being placed on a waiting list. However, there is very little funding available to purchase services, and it is not clear whether this important service would continue if the Governor's plan is implemented.

Independent living centers disburse personal care assistance checks, provide technical access assistance, offer advocacy services, and provide direct services to consumers with a broad range of disabilities. The centers are staffed by people with disabilities to provide services for consumers with disabilities. They are mandated by federal law to make their services accessible to all people with disabilities, and to do outreach to minority communities. Currently, 6000 consumers with disabilities receive services from 10 independent living centers throughout the state.

Each center provides a range of services appropriate to its area's needs. Services are not restricted to MRC clients; anyone with any disability can receive services.

If independent living services are merged with those from other agencies, such as the Department of Mental Retardation, what criteria will be used for service delivery? At MRC, consumers are allowed to take risks and live independently without being considered *at risk*. Other providers, such as DMR, place greater restrictions on their clients. At the same time, the "1-800" access model won't meet the needs of linguistic minorities, or TTY-users.

The Governor's proposal mentions independent living services, but does not refer to independent living centers; it is not clear whether the proposed area offices would disburse these services, or whether the current structure would be retained. Today, DMR consumers do not receive independent living services at specific centers. Under the proposed new structure, would consumers have to be referred separately for services?

Statewide Head Injury Program (SHIP)

Ten years ago, MRC recognized that the unique needs of people with head injuries were not being met. Many people were referred out of state to receive rehabilitation services and independent living skills. As a result, the Statewide Head Injury Program was developed. According to an advocate, SHIP'S director, Deborah Kamin, has single-handedly developed all the components of this program, saving the state hundreds of thousands of dollars. Presently, only three clients are receiving services outside Massachusetts.

Since its creation, SHIP has raised the level of awareness about consumers' needs. "This population is diverse and capable," explains one advocate. The program has educated medical personnel and human service workers about significant, but invisible, cognitive differences that exist for these consumers. Now, a community-based network of services addresses everything from independent living to substance abuse (common in this population). A small network of residential supportive living programs has been created, as well as an inpatient neuro-behavioral unit, and employment programs to enable consumers to reenter the work force, with appropriate supports. At the same time, clinicians work with families to manage people at home, and therapy groups across the state meet to provide community support.

SHIP also provides free training for professionals who work with consumers.

"The Governor's plan is devastating to people with head injuries," one advocate claims. SHIP is dissolved in this proposal, with administrative functions for residential and non-residential services split between Disability Services and Public Health Services.

Jean Turner, a Belmont resident who lives with a brain injury, testified during the hearing of the Joint Committee on Human Services and Elderly Affairs on February 13, 1996. She explained the impact of this program on her life: "I have recovered enough of my skills to return to work part-time, with lots of support from MRC's Statewide Head Injury Program. ...Employment offers true cost-containment and responsible fiscal management of employment services. House 1A does *not* fully address this issue."

Housing Registry

Fortunately, the Governor's proposal keeps the state's commitment to creating an accessible

housing registry. For the first time, consumers will be able to locate accessible rental and purchase properties in a systematic manner. A contract with the Citizens Housing and Planning Association was signed in December, and services are due to begin in April.

Line items for MRC:

4120-0020 Vocational Rehabilitation, Federal
FY1996 allocation: $36,000,000

4120-0511 Disability Determination, Federal
FY1996 allocation: $36,000,000

4120-1000 MRC Administration
FY1996 allocation: $304,286
House 1A: $309,143

4120-2000 Vocational Rehabilitation, State
FY1996 allocation: $6,306,616
House 1A: $6,306,616

4120-3000 Employment Assistance
FY1996 allocation: $6,652,907
House 1A: $6,729,825

4120-4000 Independent Living
FY1996 allocation: $3,618,446
House 1A: $3,200,814

4120-4001 Housing Registry
FY1996 allocation: $100,000
House 1A: $100,000

4120-5000 Homecare
FY1996 allocation: $3,802,590
House 1A: $3,828,626

4120-6000 Head Injury
FY1996 allocation: $6,592,046
House 1A: $6,594,994

What Can We Do?

"The plan is a decree from the top, and it is scaring those of us at the bottom — the consumers and the family members. We need to be involved in the planning process and we need to have our chance to advocate for the changes we want. We should not be left behind."
(James E. MacDonald, father)

This reaction is typical of many members of the community. It represents not only frustration, but a willingness to contribute concrete action to help resolve problems. There are many ways to take steps to make our voices heard and change our futures in a positive way.

In order for the Governor's reorganization plan to take effect it must pass through several phases in the legislature. We must make legislators aware that there is concern about proposed changes and offer suggestions which would make the plan acceptable.

The implementation of the plan is divided among 30 legislative bills and eight constitutional changes which are referred to as "Article 87's". These were filed at the end of January, 1996.

The legislative bills will pass through the regular system of approval and consideration by the House and Senate. They will then be voted upon.

The "Article 87" items have a limited period for approval. They must be voted upon by the legislature within 60 days of submission, or they automatically become law. Legislators can't make changes in these bills, but must vote to pass or reject them as they are written.

Our senators and representatives will play a key role in the acceptance or rejection of this plan. Since the restructuring encompasses all of state government, we must not assume that our legislators are familiar with the specific details in each area of the plan. Therefore, it is our job to let them know of provisions which will endanger the disability community and threaten our independent living or that of members of our families.

Educating our legislators and the public in general need not be an overwhelming task. Fear and ignorance can be conquered by those of us who have the facts and can dispel myths and misunderstandings about disability.

The best way to argue for change is to be equipped with the facts. This preparation can range from being ready to discuss personal situations to a knowledge of state laws, the ADA and specific numbers and statistics. Facts are the reasonable weapons which can destroy hyperbole.

Joining a local advocacy group for the area of your concern is a wonder-

ful first step in voicing concern. These groups disseminate useful information on everything from medical updates to proposed laws and local support available to individuals and families.

It is valuable to stay in close touch with your own legislator. These are real people selected from your own community; they should not intimidate you. Most are perfectly willing to sit down and hear your concerns. If they aren't, perhaps that is your first lesson for the next election.

A visit to the State House is not required. Letters and telephone calls from constituents are respected by legislators. These keep them in touch with their communities, familiarize them with hot-button issues and show them where voters stand. Legislators also have offices in their own districts and will meet with people locally.

It is often difficult for persons with various disabilities to make their views known. This may result from a speech or hearing impairment or it may be a matter of mobility to get to meetings and officials. Again, a letter, a phone call, joining an organization or a local group are all methods of letting someone know that you exist and indeed, matter.

Simple activities of daily living and conversations with friends also make a statement to the public. When members of the disability community and their families and friends speak openly about the reality of disability as opposed to the stereotypes, we are contributing a useful service. The public at large must become aware of cutbacks in those services which are essential for maintaining our lives, lack of access to buildings and events and the fact that every member of the community deserves respect and opportunity.